

# Needs and experiences of adolescents with CHD and parents in the transitional process - a qualitative study

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## HIGHLIGHTS

- Adolescents and parents have mixed feelings about leaving pediatric care.
- Both express a need for adequate preparation and personalized guidance and seem to be less anxious about the transfer if they are well prepared and informed.
- Improving the adolescents’ disease-related knowledge is reassuring for parents and may facilitate handing over responsibilities.
- Joint transfer consultations and a transition coordinator seem to be of great importance for a fluent transitional process, especially in establishing new treatment relationships.

**INTRODUCTION** Most patients with congenital heart disease (CHD) need lifelong cardiac follow-up. Transitioning to adulthood and transferring to adult-focused care is often challenging. We explored the **experiences and needs of adolescents with CHD and parents during the entire transitional process**, including the post-transfer period.

**METHODS** We performed a **qualitative study** according to the phenomenological approach. Semi-structured individual interviews were carried out after being transferred to adult care. Data were analyzed with inductive thematic analysis. Data collection and analysis of both samples were done separately, after which results were merged to discover common themes.

Characteristics	Adolescents	Parents
n	9	12
Average age (y)	17,8	49,8
Child’s average age (y)	-	18,4
No. of female	3	9
No. of daughters	-	6
(Child’s) CHD complexity*		
Simple (n)	1	1
Moderate (n)	5	2
Complex (n)	3	9



**HAVING MIXED FEELINGS ABOUT LEAVING THE PEDIATRIC CARE** Parents regarded the **pediatric cardiologist as a confidant** and were grateful for the efforts during the longstanding treatment relationship. Therefore, it was extra hard to say goodbye. Adolescents had **mixed feelings**.

**BEING PREPARED AND INFORMED** Most adolescents preferred to talk about the transfer earlier. They were still **overwhelmed and left with questions** after the announcement of the last pediatric outpatient visit. Parents confirmed this lack of information. Both adolescents and parents **were nervous** due to this lack of information. Framing and explaining the transfer would smooth the transfer for some parents.



**BEING ACCOMPANIED DURING CONSULTATIONS** All adolescents were accompanied during the transfer consultation and appreciated this. It gave them **a sense of assurance** and a possibility to ask for help. According to adolescents, **parents should reduce their input** during the consultations. Parents would accept their child’s wish to visit independently. Notwithstanding that it would be hard.

‘I was afraid that they would say: please wait outside’

‘It goes deeper. It has nothing to do with preference ... It is just that the difficult moments stay with you’

‘This (joint transfer consultation) is a real transfer. You do not have to start over again with someone who does not know you’



‘On the one hand, I was proud to leave the pediatric ward, but on the other hand, I regretted this. I was just starting to know him (pediatric cardiologist)’

‘Who will be my new care-team? How do things work at the adult ward?’

‘Yes, it was just so sudden to hear at the end of the appointment: next year you will go to the adult ward’



**SHIFTING RESPONSIBILITIES AND ROLES** Adolescents experienced that most communication was directed to the parents. Parents agreed, but already experienced **role changes** in pediatric care. Some parents acknowledged that the intensive period of caring could result in over-protection. Adolescents were positive about practicing with **autonomous communication** but agreed with the parents not to impose.

**GAINING TRUST IN NEW HEALTHCARE PROVIDERS** All adolescents were transferred via the joint transfer consultation with **presence of the pediatric cardiologist**, which was reassuring for both. It was also seen as a good start for a new treatment relationship for most parents. Several parents indicated the **transition coordinator** as an important transition figure and a person you can count on.

